

Aberystwyth University

Evaluation of resources to support production of high quality health information for patients and the public. Final report for NHS Research Outputs Programme

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Publication date:
2003

Citation for published version (APA):

Durbin, J., Urquhart, C., & Yeoman, A. (2003). *Evaluation of resources to support production of high quality health information for patients and the public. Final report for NHS Research Outputs Programme*. Prifysgol Aberystwyth | Aberystwyth University. <http://hdl.handle.net/2160/216>

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**EVALUATION OF RESOURCES TO SUPPORT PRODUCTION OF
HIGH QUALITY HEALTH INFORMATION
FOR PATIENTS AND THE PUBLIC**

**FINAL REPORT
FOR
NHS RESEARCH OUTPUTS PROGRAMME**

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APRIL 2003

Contents

1.0	Executive Summary	2
2.0	Scope of project	4
	2.1 Aims	4
	2.2 Objectives	4
3.0	Methods.....	4
	3.1 Mapping	5
	3.2 Review of the analysis of evaluation comments provided on the DoH toolkit ..	5
	3.3 Environmental scanning.....	5
	3.4 Stakeholder interviews.....	5
	3.5 Email questionnaire survey of PALS managers	6
4.0	Findings.....	6
	4.1 Do these resources provide a comprehensive set of resources?	6
	4.2 Are the resources complementary?	9
	4.3 Supplementary support for ‘new’ producers of information	10
	4.4 Promoting use of the resources	12
	Appendix 1 Mapping matrix	15
	Matrix category 1 Format and font	15
	Matrix category 2 Style and language	17
	Matrix category 3 Audience (targeting) and purpose	20
	Matrix category 4 Visual aids (charts, pictures) and templates	22
	Matrix category 5 Accuracy of content (facts and figures) and credibility	23
	Matrix category 6 Project management of the process	26
	Matrix category 7 Value added summary	30
	Appendix 2 Email questionnaire.....	31
	Appendix 3 Literature overview	35

1.0 Executive Summary

1.1 The project required a rapid evaluation of resources aimed at supporting the production of high quality health information for patients and the public. The resources were:

- The Toolkit for producing patient information, Department of Health
- Handbook in preparation by the Centre for Health Information Quality (CHIQ)
- Guidance produced by the King's Fund (new edition, just published, of the PoPPi guide)
- Website 'Hi Quality' produced and maintained by CHIQ

1.2 The resources provided comprise a comprehensive, and to some extent complementary set of resources. Respondents mentioned some other resources used (e.g. The Plain English Campaign) but there was no obvious gap. Concerns of some respondents for more advice on project management, and dealing with ethnic minority groups, are covered in the PoPPi guide, as is advice on obtaining financial support, another concern for some. In future, there may need to be more specific advice on communication of risk, although this is covered in the PoPPi guide. Agencies such as the National Patient Safety Agency may provide further guidance in this area.

1.3 The newer resources (DoH Toolkit, CHIQ guidance and the new edition of the PoPPi) provide a complementary set of resources. The PoPPi guide is very informative, and seems best suited to meet the needs of PALS and patient information centre producers. It refers to the DoH Toolkit and provides more justification and more advice in some important areas. The DoH Toolkit is broad-ranging, and provides a good baseline. The CHIQ guidelines provide good illustrations of good and bad practice in writing.

1.4 PALS managers, and others in charge of producing patient information in Trusts are a very diverse group. Many of our respondents were very committed to their role. Their training and support needs are difficult to categorise, and the term

‘workplace learning’ would probably fit this group very well. Many turn to available in-house training before approaching external training providers. The website ‘Hi-Quality’ does provide classified lists of training providers and courses (as well as some more online resources) and this provides another useful resource, provided PALS managers are aware of this resource. Some rating of the suitability of the courses listed for different types of staff might enhance the value of this resource.

- 1.5 The evidence from the rapid evaluation suggests that the DoH Toolkit provides a good baseline for most PALS services and patient information producers. Most services could develop their own guidelines and checklists based on the Toolkit. This adaptation may not appear cost-effective, but their own badge on guidelines often provides the necessary local ownership (as well as the ‘corporate communications’ image) to engage clinicians. A revised Toolkit could point to the other resources, to supplement advice and guidance in areas of project management, supplementary training (formal courses and informal, workplace learning), and examples of good (and bad) practice. Advice provided by the resources was rarely contradictory, and the minor differences, for example, in font/typeface recommendations should be tolerable within the NHS Identity ethos.

2.0 Scope of project

The scope, as detailed in the tender, comprised a rapid evaluation of resources aimed at supporting the production of high quality health information for patients and the public. The specific resources for evaluation set out in the brief were:

- The Toolkit for producing patient information, Department of Health
- Handbook in preparation by the Centre for Health Information Quality (CHIQ)
- Guidance produced by the King's Fund (new edition, just published, of the PoPPi guide)
- Website 'Hi Quality' produced and maintained by CHIQ

2.1 Aims

The aim of the rapid evaluation was to assess the extent to which these resources meet the needs of a variety of possible guideline users. As specified (but altering the order in the brief slightly) the key questions to be answered were:

- 1) Do these resources, in total, appear to provide comprehensive support, or are there other key resources that need to be considered?
- 2) Do these resources provide complementary support? Are some resources more suited to particular groups of people producing health information for patients and the public? Is, therefore, the target audience of information producers clear?
- 3) Is the extent of supplementary support (e.g. other material and services) available on the 'Hi Quality' Website sufficient for 'new producers' of such health information?
- 4) Are these resources likely to appear helpful? Are they easy to use, and are they credible for the target audience? How might the possible benefits of their usage be made apparent to information producers? Will the resources integrate into current and proposed procedures?

2.2 Objectives

The objectives were to:

- Assess the comprehensiveness of the resources, identifying any gaps and resources that might fill those gaps and are suitable for the UK health sector
- Assess the extent of overlap in advice given, noting any possible conflicts, and identifying whether some resources are targeting particular groups of producers, purposes of health information provision, or formats (e.g. paper /audio/ Internet)
- Identify the unique value provided by the various resources, including consideration of the supplementary resources and support signposted in the resources.
- Evaluate the presentation formats used (e.g. checklists, theme-based approaches or more in-depth discussion of issues)

3.0 Methods

A rapid evaluation required a mix of techniques to provide the answers required in a short time period. The methods undertaken are outlined as follows.

3.1 Mapping

The resources were mapped using one of the resources, the DoH Toolkit as the anchor. The mapping identified :

- elements common to more than one resource
- elements unique to any one resource
- added value features for particular resources, that might, for example, assist in staff training or provide assistance for particular types of information

The mapping matrix (Appendix 1) also provided a basis for assessing whether it was possible for a resource user to check easily whether they were complying with the advice.

The main categories for the mapping were:

1. Format and font
2. Style and language
3. Audience (targeting) and purpose
4. Visual aids (charts, pictures) and templates
5. Accuracy of content (facts and figures) and credibility
6. Project management of the process
7. Value added summary

3.2 Review of the analysis of evaluation comments provided on the DoH toolkit

The DoH (via Lorna Demming, NHS Communications) provided the evaluation report¹ based on the feedback forms supplied for the DoH toolkit. Users of the Toolkit were invited to submit comments to the Centre for Health Information Quality. For the rapid evaluation, the review of the CHIQ report focused on the questions specified.

3.3 Environmental scanning

A brief literature review was conducted to identify any evidence for the effectiveness of such resources in a variety of situations, and to help identify the range of purposes (treatment, conditions etc.) involved, and the main problems. The literature review also aimed to identify some possible future needs emerging, for example, from recent requirements for informed consent and

3.4 Stakeholder interviews

Telephone interviews (and one face to face interview) were conducted with a variety of people responsible for the quality of health information produced for patients and the public, using a semi-structured interview format.

Interviews (15) were conducted with:

- 9 PALS/Patient Information/Communications managers
- 1 PALS staff, National Patient Safety Agency
- 4 patient support group staff (Diabetes UK, Arthritis Care, National Osteoporosis Society)
- 1 clinical directorate manager

In view of the low response to the email questionnaire (Section 3.5) interviews with more PALS or patient services managers (than originally intended) were arranged at short

¹ NHS Toolkit Report. Prepared by CHIQ for NHS Communications, by Jane Shaddock and Judy Walker. Help for Health Trust, February 2003.

notice. It proved difficult to arrange interviews with health professionals, which meant that questions and interviews with PALS managers (or equivalent) included more detail about their procedures for working with health professional staff on the production of information for patients and the public.

3.5 Email questionnaire survey of PALS managers

A short questionnaire to PALS managers (Appendix 2) was emailed to 100 PALS services listed on the EQUIP Website². A reminder was sent to those services which had not responded. Response was poorer than anticipated (27 responses), although those who did respond often provided many additional comments. The most probable reason for poor response was that the questionnaire could not be sent to a named individual, and in such circumstances, those receiving may play 'pass the parcel'. As indicated above, additional interviews were arranged to compensate. Questions asked about the main priorities for quality assuring information for patients and the public, the support and training required for PALS staff and others involved in this work, and how such training and support was implemented.

4.0 Findings

Findings are arranged as answers to questions specified in the brief, and the letter of agreement.

4.1 Do these resources provide a comprehensive set of resources?

Do these resources, in total, appear to provide comprehensive support, or are there other key resources that need to be considered?

- 4.11 Answers to email questions about the use of guidelines, and training indicated that most PALS services (78%) had used the DoH Toolkit, and nearly half (48%) had used either the PoPPi (King's Fund) guide or the CHIQ (Hi Quality) Website. Of those (44%, 12/27) who had used other guidelines, there was no predominant external source of support, the most common theme being reliance on some type of in-house guidance or standards for patient information (5 comments). Other comments concerned compliance with guidance from other government agency sources (Modernisation Agency, NICE/NSF).
- 4.12 Interviews indicated that such resources provided a basic platform '*The Toolkit is a good starting point*' but many of the services were developing their own guidelines. Some had particular areas of concern (e.g. dealing with ethnic minorities, mental health patients and their carers). For them, resources such as the Toolkit would need to be expanded.
- 4.12 The CHIQ report on the DoH Toolkit evaluation forms was equivocal on the comprehensiveness of the toolkit. Only 16 (out of 73) feedback forms expressed an opinion, and of those, five thought something was missing (e.g. advice and training, communication of risk), seven did not think anything was missing and four could not expressly make a judgment either way. Of the 28 respondents who expressed an opinion on the helpfulness, 85.7% felt the Toolkit guidance was helpful.

² <http://www.equip.nhs.uk>

- 4.14 At present the needs of the PALS services vary. Some are based on well-established services, with a team of experienced staff. Others are in the early stages of establishing systems. The email questionnaires indicated that most provide information on NHS services (e.g. factual information on clinic times), details of voluntary and support groups, contact details for specialist services, advocacy and complaints, and also health information. Welfare information (e.g. benefits, continuing care grants) was also mentioned.
- 4.15 The matrix mapping indicated that the area that was weakest (overall) was in the area of project management of the process of producing information for patients and the public. In other areas, much of the advice in the four resources replicated or expanded what the other resources provided. At this stage of existence, many PALS services are setting up structures to co-ordinate the production and monitoring of patient information with their organisation. The immediate priorities are (in descending order of importance):
- presenting information for non-native speakers of English (a particular problem for Trusts in some urban areas)
'There are 250 languages spoken and in some of our inpatient wards we will occasionally find situations where there isn't a single patient whose native language is English' (PALS manager, London)
 - co-ordinating the collection of information and views from patients and the public
 - co-ordinating the collection of information and views from expert patients
 - co-ordinating the collection of information and views from health professionals
 - briefing designers
 - communicating information about risks and benefits of treatment
- Dealing with language, interpretation and translation services can be difficult. For some ethnic groups, much of the patient information literature needs to be published on tape, as some of these groups are not fully literate in their own language. Translation is not a simple process, as it is more a process of adaptation than straight translation. For example, different cultures view mental health problems in very different ways.
- 4.16 Other interviews also stressed the importance of a production structure within a Trust, particularly when leaflets might be made available via the Trust Web pages. In other words, advice on making content accurate and relevant is all well and good, but consistency in production, maintenance, review and updating will ensure that the 'brand image' of leaflets from the Trust is something patients and the public will trust and rely on. For example, in one Trust the production process involves:
- expression of interest in writing a leaflet (to help in planning for the possible special needs of the audience – learning difficulties, communication problems, language needs)
 - authorisation (linked to validation)
 - writing and vetting (through the Patient Information Group)
 - piloting with patients with the condition/treatment (using a questionnaire developed for the purpose)
 - review and updating

In this Trust the evidence in patient information leaflets is referenced, as this helps with the updating process. Another general resource mentioned were guidelines from HSRU, Aberdeen³.

- 4.16 Comments (questionnaire and interviews) suggested that priorities may change as the PALS service mature. On communicating risks, for example,
'I think it is fraught with difficulties, pitching it at the right level, giving patients enough information at the right time when they are ready for it, and giving them enough, not too detailed, not too little' (PALS manager)
DISCERN guidelines⁴ are used by some to help them in presentation of information on treatment choices, and there is likely to be more emphasis on risk communication in future.
- 4.17 One frequent theme from the interviews was the problem of funding the production of information, particularly when there are financial constraints within the Trust.
'I'm absolutely passionate about the fact that we should be putting information out that looks professional but when our public knows that we're financially deeply in the red...they wouldn't want us to spend on that when health provision's been cut in the locality' (PALS manager)
Comments from the CHIQ report echo the need to make the production more efficient (and hence cheaper). Sponsorship is an established practice for many services.
- 4.18 Synthesising the results, the principal concern of many PALS/patient information services is the production process. The project management issues set out in Matrix category 6 detail most of the elements of the process of creating, monitoring, providing access, and reviewing the leaflets produced. Such concerns are also echoed in the recommendations of the CHIQ report (p.15) on the Toolkit, where the recommendations include:
- offer information about suitable training for producing patient information
 - offer guidance on suitable translation services
 - provide advice on implementing a quality control audit and monitoring process for patient information leaflets
 - include guidance on the review process
- 4.19 In summary, the resources appear comprehensive in scope at present (there was no other frequently mentioned resource). The present priority for many PALS and patient information services is project management of the production process, and future needs might focus more on presentation of the evidence, and risks.

³ University of Aberdeen, Health Services Research Unit. *Guide to producing health information*. <http://www.abdn.ac.uk/hsru/guide.hti>

⁴ Shepperd S, Charnock D, Cook A. A 5-star system for rating the quality of information based on DISCERN. *Health Information and Libraries Journal* 2002; 19(4): 201-206. (<http://www.discern.org.uk>)

4.2 Are the resources complementary?

Do these resources provide complementary support? Are some resources more suited to particular groups of people producing health information for patients and the public? Is, therefore, the target audience of information producers clear?

- 4.21 The email questionnaire responses showed that eight (30%) service managers had used, or consulted all three resources. Most of those eight used other resources as well. Of the seven who did not use resources other than those listed, all had consulted the Toolkit. The evidence is very slim, but it seems possible that producers may fall into two camps, those who will always seek out a variety of resources, and those who rely on one main resource.
- 4.22 Interviews indicated that most PALS /patient information managers were aware of the difficulties of producing good quality information. Writing skills are very important, and people with a journalistic background often have the skills required. These skills can be developed but following a rule book will not guarantee a quality result. Within Trusts, communications departments may lend support. Interviews, and the anecdotal evidence from the ‘pass the parcel’ experience with the email questionnaire, point to the variety of skills and roles within the patient information/PALS teams. Efforts to locate health professionals as producers of information were less successful as the reaction was that the interviewers should talk to the people who deal with patient information – the PALS or patient information services, or PR/communications staff. That in itself may indicate that health professionals now see that there is properly a role for patient information provision and that it is a Trust-wide responsibility.
- 4.23 Comparisons of resources from the mapping (Appendix 1) suggest that:
- format and font recommendations are very similar, with the PoPPi guidelines cross referenced to the Toolkit. The Toolkit has more specific guidance than either the CHIQ guidelines or the Hi-Quality website. The CHIQ guidelines include some examples of good and bad practice.
 - style and language recommendations are similar, with CHIQ guidelines giving examples, and PoPPi providing additional, more detailed background
 - audience (targeting) and purpose are covered in the Toolkit, and the Toolkit provides the most comprehensive list of types of audience to be considered.
 - visual aids and templates are covered in the Toolkit, with the Hi-Quality checklist mentioned as a ‘quick checklist’.
 - accuracy of content (facts and figures) and credibility are considered in various ways. The Toolkit, for example, seems to have less to say about acknowledgement of commercial support than the other resources. PoPPi has specific advice on the process of patient involvement, professional involvement (and conflicts of interest), as well as advice on quality assurance processes.
 - project management advice is provided in depth by PoPPi, whereas the Toolkit and the other resources do not usually provide as much detail. The Hi-Quality website provides classified lists of training providers and other online resources.

- 4.24 Interviews indicated that many Trusts are developing their own guidelines, which are based on one or more of the available resources, as part of the process of getting staff to feel responsible (to 'own') the production of information for patients and the public. Nearly half the email respondents had produced their own checklist. It is also one way of selling the process to staff who may be more inclined to participate in a production of a leaflet produced to 'their' in-house guidelines, rather than defer to external guidelines. This approach may change once the CHIQ guidelines are fully published, and the PoPPi guidance has reached the audience, but it seems, from the interviews, that local ownership is important for local acceptance of the processes of producing quality information.
- 4.25 A summary of the value-added components of each resource (matrix category 7) indicates:
- DoH Toolkit
 - Strengths: national standard, broad range of aspects covered
 - Weaknesses: more detail might be required for some users, particularly in project management, justification of the reasons for particular advice
 - CHIQ guidelines
 - Strengths: has examples of good and bad ways of presenting information, list of useful websites, good list of key points
 - Weaknesses: not as comprehensive, or as broad ranging as the Toolkit or the PoPPi guide
 - Hi-Quality website
 - Strengths: quick checklist, useful as an introduction, established resource, comprehensive list of external training providers and other online resources provided
 - Weaknesses: may appear to some to be a shopping list, a reference to advice rather than immediate authoritative advice
 - PoPPi
 - Strengths: very thorough, and provides 'evidence' for the advice and processes recommended. Has good coverage of the project management processes and provides comprehensive list of further resources and sources of funding
 - Weaknesses: possibly too detailed to be given to busy health professionals

4.3 Supplementary support for 'new' producers of information

Is the extent of supplementary support (e.g. other material and services) available on the 'Hi Quality' Website sufficient for 'new producers' of such health information?

- 4.31 PALS/patient information managers acknowledge the need for staff training and support, and 70% had sent staff to workshops or other training. The most common training provider was in-house provision (41%), followed by CHIQ or NHS. A range of training/consultancy firms were mentioned, with some university provision.

- 4.32 Views on the need for specific training (e.g. CHIQ courses, King's Fund training) as opposed to the ongoing support that might be provided by online support (e.g. through a Website) suggested that handling graphics, and presentation of statistics were the activities that required a greater emphasis on training events. Working with professionals, and working with patients and support groups required specific, and ongoing support (Table 1). On this slim evidence, there is a need for specific advice, training and support on style, presentation, and content. For other activities, even defining the skills might be difficult, as experience counts for a lot and the knowledge is tacit rather than explicit. But the experience of years

'I have never in 15 years seen a leaflet walk into my office that could be published...what you need is a professional writing skill to turn the idea...into something in the right language, in the right words' (PALS/PR manager)

needs to be shared in some way, particularly when financial constraints mean that many PALS try to do as much work in-house as possible.

'(Sending out to design consultants...)..it's very rare, if we're short on time, but because of the cost implications we try and do everything in-house' (PALS manager)

Activity requiring skill support	Specific training and support (only)	Ongoing training and support (only)	Both
Involving health professionals	1	4	17
Involving patients and the public	2	3	19
Writing 'readable' text	9	1	12
Adopting an appropriate style for the audience	8	3	10
Ordering text and graphics	11	1	8
Making appropriate use of multimedia	7	2	13
Presenting statistics and the evidence	13	2	9

Table 1 PALS views on specific and ongoing training and support

- 4.33 Marketing skills, knowing what the market requires and how the product (leaflet) will be used, are important. That requires a structure that maintains and develops relationships with the health professionals as well as with patients and patient support groups. It would be easy to fall into the trap of assuming that 'one size fits all' for level of patient information, but that is not appropriate for many long-term conditions. One patient support group dealing with 'expert patients' pointed out that their market research showed that their patients wanted information, and lots of it. A PALS manager expressed the need for some flexibility of approach:

'We work very closely with voluntary organisations...but the whole issue is if you recognise people have different communication needs you are recognising that ...you can't have a one size fits all information strategy. You need to have financial resources in terms of producing stuff...to produce things in all kinds of different ways and distribute them in all kinds of different ways' (PALS manager)

4.34 The matrix mapping suggests that the quick checklist provided by the Hi-Quality website might be useful as an introduction to the type of issues that need to be considered, and could be used as preliminaries to further training (e.g. as listed on the Hi-Quality site). The PoPPi resource provides more detail, and seems to provide the type of information, and pointers to further resources, that might be useful to PALS staff who have not previously worked in the health sector. The examples in the CHIQ guidelines illustrate points that might be overlooked in checking through a document. The PoPPi guidance gives more advice on writing style (storytelling) and readability tests than the other resources. Patient and professional involvement is discussed in more depth in the PoPPi guide, complementing the advice provided in the Toolkit for specific audiences. Project management and quality assurance processes are considered in depth only in the PoPPi guide.

4.35 In summary, the type of training required varies considerably, and the phrase ‘workplace learning’ fits the situation here very well. The Hi-Quality website has a list of external training providers and other resources that could provide a good starting point for specific training and ongoing support. The PoPPi guidance gives good background advice on the major project management and quality assurance requirements. Some rating of the suitability of the courses for particular groups of staff (on the Hi-Quality website) might be popular among PALS staff who are weighing up the benefits of sending staff for external training.

4.4 Promoting use of the resources

Are these resources likely to appear helpful? Are they easy to use, and are they credible for the target audience? How might the possible benefits of their usage be made apparent to information producers? Will the resources integrate into current and proposed procedures?

4.41 Interviews indicated that many PALS were in the early stages of assembling their teams, assessing the ‘skill-mix’ and developing those skills. They may rely on voluntary groups to provide not only the patient perspective but also the experience of ‘patient involvement’. Many patient support groups have structures which can assist in this formally, and will advise on specific needs (e.g. for visual impairment with diabetic patients, or needs of specific ethnic groups that are susceptible to the disease). Patient support groups with a national structure can often pool resources, with a group in one area producing a video that can be used throughout the country by other groups. Email questionnaires indicated that PALS often collate, check and co-ordinate in a variety of ways. Most (70%) use a health professional or patient panel to quality assure a leaflet, and interviews indicated that those who do not use a panel may still be at the stage of auditing what is produced within the Trust, or else they may circulate drafts in another way. Many staff might be involved, and this is a time consuming process, often around six months, sometimes longer.

4.42 The CHIQ report (on the Toolkit) indicated that the guidance was clear (27/28) and helpful (24/30). Experience of using the templates was limited, and comments suggest

that producers tend to develop their own ways of doing things, as the range of comments disagreeing with some parts of the guidance indicates.

'Use of Frutiger – easier to read a serif face.'

'Sans serif can be bleak, cold, uninviting- the opposite of what the NHS should represent'

'Judicial use of italics lends variety and shouldn't be banned' (CHIQ report, p.9)

It may be more politic to allow for some variation in approach as far as format and style are concerned, as it seems impossible to please everyone on this. Issues of appearance, font and typeface generated a large number of contents in the feedback evaluation of the Toolkit (CHIQ report p.8-9), and the recommendations (p.15) suggested providing a Word version of the templates, as well as clarifying whether the Toolkit is compulsory.

- 4.43 Making benefits credible depends on the background of those concerned. The main groups include the PALS/patient information service staff, health professionals, patients and patient support groups. Professional values are likely to influence views of the authority of resources or guidelines produced by central government, professional bodies or external consultants, training providers.
- 4.44 PALS/patient information service staff come from diverse backgrounds. Those who come from a journalistic background may think in terms of the Plain English Campaign for support and guidance. They may already have their own preferences for software, and format. Readability tests, for example, are used by just under half the respondents. Responsibilities are shared, with health professionals responsible for the factual and clinical accuracy (8 similar comments), while patients check for readability and understanding (11 similar comments). For those new to the NHS, some support may be necessary on particular needs for patient information and the public. That may include:
- developing processes for the creation, maintenance and review of information for patients and the public
 - setting up liaison mechanisms with groups of professionals, patients and support groups, as well as with local translation services
- For junior PALS staff, the CHIQ guidelines illustrate good and bad writing practice.
- 4.45 Health professionals may be convinced of the need for a professional approach to production of information for patients and the public by:
- 'seeing is believing' - seeing a leaflet produced for another department
'staff will see a leaflet that has been professionally produced, they'll like it, they'll want something similar' (PALS/PR manager)
 - guidance from a body they 'know'. Local guidelines, based on national guidelines from the DoH, are likely to be judged more trustworthy than other externally produced guidelines.

The literature evidence emphasises that health professionals, left to their own devices, consistently produce literature that is not readable, by the standards of a variety of readability tests. In addition, as one PALS manager noted:

'Staff are often not aware...that what we want patients to know and what patients want to know...(are)...two totally different things and that's a huge divide that really takes a lot of crossing' (PALS/PR manager)

It is hard to convince health professionals that it is not too ‘*Mickey Mouse*’ if technical terms are not used. On the other hand, expert patients may want a lot of information, but not the information that professionals might see as important. The literature review (Appendix 3) indicates that using guidelines and other evidence to make leaflets more understandable does produce leaflets that both patients and professionals like. Making the leaflet more readable does not necessarily mean that there should be less information and the review suggests that one problem is that many leaflets do not have sufficient information for patients to make informed choices about treatments.

- 4.46 In summary, most PALS/patient information centre services need to adapt, or be seen to adapt any centrally produced guidelines to provide the necessary local ownership. To preserve the benefits of efficiency and effectiveness of central direction and support, producers should be encouraged to use one resource, the DoH Toolkit, as their baseline. The PoPPi guide complements the DoH toolkit well in the area of project management, and dealing with the special needs of some groups (such as ethnic minorities). Similarly, the other resources add value to the DoH Toolkit in other respects, and may help some staff with particular queries. Revisions to the Toolkit should point to the other resources at appropriate points, as indicated in detail in the mapping.

Appendix 1 Mapping matrix

Matrix category 1 Format and font

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Advice on appropriate formats	Yes (p.5 let people know of other formats and Appendix 2)	Yes (pp.32-33 refers to need to consider appropriate formats to meet the needs of users in relation to Disability Discrimination Act.	Yes (Producers Guidelines) mentions alternative languages/formats and advice can also be found in 'Communicating Clearly' within the Quality Standards	Yes (Section 5 covers this and refers people to the DoH toolkit for the specifics, so therefore the advice is the same as the toolkit
Short sentence recommendations	Yes (p.6)	Yes (pp.29-30 with examples)	Yes ('Producers Guidelines)	As above
Lower case letters	Yes (p. 6)	Yes (p.22 with examples)	Yes ('Producers Guidelines)	As above
Tenses – present and active	Yes (p.6)	Yes (p.29 with examples)	Yes (Producers Guidelines)	As above
Font size no less than 12	Yes (p.6)	Yes (p.20 with examples)	Yes (Producers Guidelines)	As above
Large bold font for emphasis	Yes (p.6)	Yes (p.12 with example but also suggests limited use of italic is acceptable although underlining is discouraged)	Yes (Producers Guidelines)	As above
Numbers style (1-10 written, over 10 as numbers)	Yes (p.6)	No	Yes (Producers Guidelines and 'Communicating Clearly')	As above

(Matrix category 1 Format and font, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Use of white space	Yes (p.6)	Yes (p.25 says that lines should be clearly spaced and p.27 says unrelated sections should be clearly separated and labelled)	Yes ('Producers Guidelines') – lines of type should be clearly spaced and unrelated sections separated	As above
Full justification of text to be avoided	Yes (p.9)	Yes (p.26)	No	As above
Small blocks of text	Yes (p.6)	No as such but does talk about separating sections (p.27)	No but does talk about separating sections ('Producers Guidelines')	As above
One condition or treatment per leaflet	Yes (p.5)	No	No	Not specifically mentioned (?) but section 5 stresses the need for simplicity when presenting information about conditions
Print contrast	Yes (p.9)	Yes (pp.20-21)	Yes ('Producers Guidelines')	Refers to DoH Toolkit as above
Sans serif font	Yes (p.9)	Yes (pp.19-20 with examples)	Yes (Producers Guidelines and 'Communicating Clearly' suggest using Ariel)	As above
One or two colours	Yes (p.9)	No	No	As above
Design and layout should be consistent	Yes through the consistent features (p.8) and the templates	Yes (p.3 with examples and p.28)	Yes (Producers Guidelines)	As above

Matrix category 2 Style and language

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Question and answer format	Yes (p.6)	No	No	Refers to DoH Toolkit as above
Use of bulleted or numbered points	Yes (p.6)	Yes (pp.24-25 with examples)	Yes (Producers Guidelines)	As above
Use of everyday language (no jargon)	Yes (pp.4, 5,7)	Yes (pp.30-31 with examples)	Yes (Producers Guidelines) also says acronyms etc. should be explained in a glossary. There are also links to the Plain English Campaign and Basic Skills Agency from 'Communicating Clearly'	Yes (section 5 considers use of plain English and readability tests)
Use of patient friendly text – personal pronouns	Yes (pp.4,5)	No but one the examples in the clear language section does advocate use of personal pronoun along with active tense	Yes (Producers Guidelines). 'Communicating Clearly' urges giving advice rather than orders	Yes (section 5 gives guidance on writing style)
Relevance to the individual	Yes (p.5 though not sure how to achieve this if writing for a group of patients)	Yes (p.35 says that the aims of the resource should be clearly defined, based on the needs of the target audience and should be stated on the resource)	Yes target group should be clearly defined and aims of resource clearly stated (Producers Guidelines)	Yes (section 5 considers story-telling as a way of making information accessible and relevant to the individual)

(Matrix category 2 Style and language, continued)

	DoH toolkit	CHiQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Reinforcement of information supplied (clinic)	Yes (p.5.)	Yes (p.7 through signposting to related health information resources, with examples)	Yes (signposting to related resources – in Producers Guidelines and 'Communicating Clearly')	This is covered by the discussion on information strategy in section 1, Building on existing information in section 3 and collecting the evidence in section 4
Information placed in context with other information supplied and not conflicting	Yes (pp.5,7)	Talks about messages not contradicting themselves (p.2) but focuses on contradictions within the same document	Talks about messages not contradicting themselves (Producers Guidelines) but focuses on contradictions within the same document	As above
House style	Yes (through templates in Section 2 and pp. 8-9)	No but talks about the importance of consistency in design, layout and text (pp.2-5 and p.28) to generate a feel of professionalism and boost confidence	Yes (brand should be instantly identifiable, also ensure a House Style is in place and referred to – in Producers Guidelines). Also 'Processes and Systems' gives ideas about what to include and resources to help	Does not promote a particular house style but stresses the need to consider corporate presentation standards and also uses the DoH toolkit style guidelines (section 5)

(Matrix category 2 Style and language, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Messages do not contradict themselves	Yes in relation to messages being in context with other information but not specifically within the same document	Yes (pp.2-3 with examples)	Yes (Producers Guidelines)	Yes (p.45 says that information should be clear and unambiguous but doesn't specifically mention contradiction within a document)
Language and terms should be consistent	Not specifically mentioned	Yes (p.4 with examples)	Yes (all documents should be proofread – Producers Guidelines)	Yes (section 7 looks at piloting and checking of drafts but detailed proofreading for grammar etc. not mentioned)

Matrix category 3 Audience (targeting) and purpose

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Ensure information given at an appropriate time	Yes (p.7)	No	No	Not specifically mentioned except as part of the evaluation process (section 9)
Providing information: operations, treatments or investigations	Yes (Appendix 1.1)	No	No	Yes (section 5 lists key information to include – uses the subheadings: clinical information/inpatients/outpatients and day cases/additional information/information on medicines/information on clinical trials but covers all these issues. Also looks at presenting performance tables and the issues around copying letters to patients)
Providing information on conditions and treatments	Yes (Appendix 1.2)	No	No	As above
Providing information on services/clinics	Yes (Appendix 1.3)	No	No	As above
Providing information on medication	Yes (Appendix 1.4)	No	No	As above
Choosing the right medium	Yes (Appendix 2)	Yes (p.33) in relation to Disability Discrimination Act	Yes (Producers Guidelines and 'Communicating Clearly') does mention availability of other formats	Yes (section 6 covers this in depth, looks at needs of groups of patients – see below – but also stresses the need to consult patients at an early stage and respond to their preferences. Also looks at different types of media – e.g. audio, cartoons, Internet – and how they can be used)
Elderly	Yes (Appendix 2)	No	No	No specific guidelines but urges people to consider age when assessing the needs of the target audience
Not 'ill'	Yes (Appendix 2)	No	No	Not mentioned specifically but again the guidelines urge consideration of needs of target audience

(Matrix category 3 Audience, purpose, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Children	Yes (Appendix 2)	No	No	No specific guidelines but urges people to consider age when assessing the needs of the target audience
Learning difficulties	Yes (Appendix 2)	No	No	Yes (section 6)
Hearing difficulties	Yes (Appendix 2)	No	No	Yes (section 6)
Sight difficulties	Yes (Appendix 2)	Yes (p.33)	Yes 'Communicating Clearly' links to RNIB Website	Yes (section 6)
First language not English	Yes (Appendix 2)	Yes (pp.32)	No	Yes (section 6, encourages people to consider cultural issues and the use of appropriate images – adapting rather than just translating)
Reading problems	Yes (Appendix 2)	No	'Yes 'Communicating Clearly' links to Basic Skills Agency Website	Yes (e.g. in the discussion of use of Audio, section 6)
'Expert patients'	Yes (Appendix 2)	Yes (p.36 says that it is useful if patients with direct experience of a condition can be involved)	Not as such although does mention need to include members of target group in the process (Producers Guidelines and 'Involving Consumers')	Section 1 on policy refers to the Expert Patient. Section 4 on involving patients stresses the need to consider the type of patients/carers to be involved (e.g. new or existing patients), also points out that only patients can tell you what it is like to live with a condition.

Matrix category 4 Visual aids (charts, pictures) and templates

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Diagrams and pictures in accordance with NHS identity guidelines	Yes (p.6)	pp.27-28: images and diagrams should be labelled and relate to subject matter, with examples	Images and diagrams should be labelled and relate to subject matter ('Presentation' section)	Refers to DoH toolkit as above
Compliance with Disability Discrimination Act	Yes (Appendix 2)	Yes (p.33)	No although does mention other formats ('Accessible' section')	Yes (section 6)
Availability of templates	Yes (Section 2 and also guidance on pp. 8-9)	No	No	No but section 5 refers to the DoH Toolkit templates
Availability of quick checklists	Yes (Appendix 1)	No	Yes - Producers Guidelines	No but section 7 refers to other organisations that do provide quick checklists (e.g. Hi Quality)

Matrix category 5 Accuracy of content (facts and figures) and credibility

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Providing objective information for decision making concerning risks, side effects and benefits	Yes (p. 5 and also p.3 in the section on characteristics of good patient information)	Yes (objectivity implied in the section on reliability of information and through the examples (pp.11-18) but doesn't really specify what the information would be for	Yes ('Informed Consent' in the 'About' section covers this	Yes (section 1, although does not specifically mention risks, section 5 on key information also covers this and does mention risks)
Working with evidence	Yes (p.4)	Yes (e.g. p.11-12: all sources should be specified, p.13: should be based on more than one source, pp.14-15 opinion should be stated as such pp.15-16: all authors should be named)	Yes, Sources mentioned should be dated (Producers Guidelines); sources should be specified and it should be clear that more than one has been used, opinion should be stated as such, authors named. Also there is a 'Working with Evidence' section under 'About' and it is also covered in 'Processes and Systems'	Yes (section 4 deals with this and gives a list of evidence-based resources to refer to, also gives advice on presenting that evidence in an accessible way)
Acknowledgement of commercial support	(Not sure about this one. There is a point about identifying funding but it is more related to locating funding sources, e.g. for printing.)	Yes (p.14 states that all sponsorship should be declared and gives examples)	Yes sponsorship should be declared (Producers Guidelines and 'Communicating Clearly')	Yes (section 3 discusses sponsorship, it does not specifically mention acknowledgement of commercial support but refers people to their local guidelines)

(Matrix category 5 Accuracy, credibility, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Involvement of consumers/patients	Yes (p.7)	Yes (p.36 – it should be stated that members of the target group have been involved in the development of the resource, with examples)	Yes (Producers Guidelines) members of the target group should be consulted before and during production. There is also an 'Involving Consumers' section	Yes (section 4 looks at involving patients/carers in some depth)
Involvement of health professionals	Yes (p.7)	No	Yes (Producers Guidelines) says it is stated that the information has been checked by an expert in the content area. 'Processes and Systems' urges a peer review process	Yes (section 4 looks at collecting the views of professionals in the stage of collecting the evidence and considers issues such as conflict of interest).
Involvement of social care	Yes (could be p. 7 in the section on consulting interested parties but not specifically identified?)	No	No	Not specifically mentioned but section 3 urges consideration of the variety of agencies that could be involved in producing patient information
Advice on QA processes and systems (may need to be considered separately)	Yes (referred to on p.7 but doesn't give a lot of information)	Yes (pp.11-18 cover ways of ensuring and demonstrating that information is reliable. Also pp.16-17 it should be stated that information is in line with external standards)	Yes (Producers Guidelines) editorial standards/guidelines should be referred to and information peer-reviewed. Also says it should state that readers should discuss concerns with a health professional. See also all the of 'Quality Standards' section	Yes (section 7 gives details of quality standards to consider e.g. DISCERN, Hi Quality)

(Matrix category 5 Accuracy, credibility, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Information should be current and accurate	Yes (p.7)	Yes (pp.8-10 cover the importance of adding the production date to the information, showing a review date and including a publication date for all research mentioned) Gives examples	Yes (dates of production and expiry/review should be shown along with dates of sources used and copyright details – in Producers Guidelines)	Yes (e.g. section 4 stresses the need to check evidence-based resources to ensure that information is up-to-date and accurate)

Matrix category 6 Project management of the process

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Do the guidelines contextualise the role of patient information?	Yes (pp.2-4)	No	Yes in the 'Introduction' of 'Quality Standards'	Yes (section 1)
Defining the target audience	Yes (by inference through identifying need etc. e.g. p. 7)	Yes (pp.34-35 says that the target audience should be stated on the health information resource)	Yes (Producers Guidelines) says target group should be clearly defined, see also 'Communicating Clearly'	Yes (section 3)
Determine what information patients need	Yes (p.7)	Yes (p.36 says that members of the target audience should be involved in the production of the resource)	Yes (Producers Guidelines) by consulting members of the target group before and during production, See also 'Involving Consumers'	Yes (section 3 gives examples of how to do this)
Advantages and disadvantages of building on existing information	Yes (p.7)	No	No	Yes (section 3 gives advice on assessing existing information)
Timescales	No	No	No	Yes (section 3 notes that it is important to consider timescales and not to underestimate how long it will take)
Teamworking	Not specifically although p.7 highlights the need to involve others	No	No	Yes (section 3 gives advice on building a team with case-study example)
When will information be given?	Yes (p.7)	No	No	Not specifically mentioned but section 3 urges consideration of how information will be used

(Matrix category 6 Project management, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
How will process be organised?	Yes (p.7)	No	No	Yes (section 3 considers planning)
Is it part of a series?	Yes (p.7)	Yes (p.6 with examples)	Yes (in 'Continuity' section)	Not specifically mentioned but again section 3 urges consideration of how information will be used
How will it be distributed?	Yes (p.7)	No	No	Yes (section 3 looks at publicity and distribution and section 8 also considers dissemination)
Funding issues	Yes (p.7)	Yes (p.14 says that sponsorship should be declared and the relationship should be transparent)	Yes ('Communicating Clearly' refers to the need to declare sponsorship)	Yes (section 3 gives sample costings and looks at sponsorship etc.)
Support and training	No	No	Lists of training providers and courses under 'Training' section	Yes (section 3 lists organisations that can support staff development in this area)
Consider implications on the service of increasing patient awareness	No	No	No	Yes (section 3 gives a case-study to illustrate)
Briefing a designer	No but includes templates	No	No	Yes (section 5)
Check contact details, use job titles rather than naming individual	Yes (p.7)	No	No	Section 9 stresses the need to ensure that information is kept up to date but this specific tip is not given

(Matrix category 6 Project management, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Ensure a thorough proofreading /checking process	Yes (p.7)	Yes (pp.4-5 with examples) cover the need to proofread for typing or grammatical errors	Yes (Producers Guidelines) all documents should be proofread prior to publication	Yes (section 7 discusses piloting and review of drafts as part of the QA process)
Give careful thought to print-runs	Yes (p.7)	No	No	Yes (by implication, section 3 looks at production costs and section 9 at updating but the implications on print runs are not spelt out as succinctly as in the DoH Toolkit
Monitor use/feedback	Yes (p.7)	Yes (p.37 – contact details should be included and the audience encouraged to give feedback)	Yes (Producers Guidelines) contact details should be included and the audience encouraged to give feedback. See also 'Involving Consumers'	Yes (section 9)
Devise a review programme	Yes (p.7)	No	Yes (Review dates should appear on documents and out-of-date information should be withdrawn, Producers Guidelines). 'Processes and Systems recommends building current-awareness mechanism into the review process	Yes (section 9 covers this in depth looking at the importance of an annual review and suitable evaluation methods)

(Matrix category 6 Project management, continued)

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Will there be a corporate strategy on patient information and/or a central system for coordination/archiving?	Not really although p. 7 raises issues of quality assurance, coordination and monitoring	No	Mentions the need to set up a system for keeping producers up to date with key developments (Producers Guidelines)	Yes (section 2)
Legal liability	Yes in terms of Disability Discrimination Act (p.14)	Yes (p.16 copyright law should be respected, pp.17-18 give examples of disclaimers setting boundaries of organisation's responsibility)	Yes (Legal and Ethical issues are covered in 'About Hi-Quality')	Yes (section 2 give details of copyright and methods to protect against negligence claims with examples of disclaimers etc., also considers Disability Discrimination Act in section 6)

Matrix category 7 Value added summary

	DoH toolkit	CHIQ guidelines	Hi-Quality website	PoPPi (King's Fund)
Value-added	The DoH guidelines give a national standard and are a good compromise between the quick checklist approach and the very thorough approach of the PoPPi guidelines. They touch on a broad range of aspects to be considered (including coordination and organisational issues) but these are dealt with in more depth by the PoPPi guide.	This resource covers less points than both the DoH Toolkit and the PoPPi guide. This is partly because it focuses on the actual patient information document more than the process of producing it and project-management concerns. However it does have the advantage of examples to illustrate most points. Each section has a clear list of key points at the beginning and a summary box at the end. It also has a list of useful Websites at the end.	This resource includes a quick checklist covering much of the same ground as the CHIQ guidelines, which could help introduce staff to producing information for patients and the public. Compared to this checklist both the DoH Toolkit and the CHIQ guidelines are more comprehensive whilst still being accessible. However, the Website has the advantage of allowing users to link directly to other relevant Websites and it also contains a useful FAQ section.	This resource is very thorough and may be more appropriate for those coordinating the process (e.g. PALS managers) who may then wish to distil the information into a quick-reference format or produce local guidelines based on this and other resources. Added value factors include the Action Points, Case Studies, referencing and also the Listings of useful contacts, sources of project funding and Useful Websites

Appendix 2 Email questionnaire

Dear Colleague

We have been commissioned by the Department of Health to do a rapid evaluation of resources to support the production of quality health information for patients and the public. Ron Stamp, Director, NHS Research Outputs Programme, R&D Portfolio Director for Knowledge Management (DoH)

(Ron.Stamp@doh.gsi.gov.uk) is the DoH commissioner for the project.

We'd be very grateful for your help in answering the following questions. The questionnaire should take only five minutes to complete and should be completed by a manager for your service.

You may send us your reply online or by post, by TODAY is our closing date.

If replying ONLINE, you can send a reply message to me (Jane Durbin, jed@aber.ac.uk). Please put an 'X' in the appropriate question boxes and type in any further comments you wish to make, before 'sending' your reply.

If you wish to send your reply by POST, please print off the email, fill in the boxes (with an 'X') and post it to me (Jane Durbin, Department of Information Studies, University of Wales Aberystwyth, SY23 3AS).

Thank you very much for your help. This is a rapid evaluation and we are aware that some of our presentation in this questionnaire could be improved, if given more time than allotted for the evaluation.

QUESTION 1: Please indicate the main categories of information you provide for patients and the public. Information about:

NHS Services (e.g. How to find a NHS dentist). []

Voluntary sector organisations/support groups. []

Contact details for specialist services (eg. alcohol/drugs, helplines). []

Advocacy services/complaints procedures. []

Health information (eg. on specific conditions). []

Are there any other categories of information that you provide on a regular basis? Please give details.

QUESTION 2: Your main priorities and problems in producing information for patients and the public. Please put an X in the relevant boxes.

2.1 Collecting information from health professionals is: a major ☐ problem/ a minor ☐ problem.

2.2 Collecting information and views from patients and the public is: a major ☐ problem/ a minor ☐ problem.

2.3 Presenting information for patients whose first language is not English is: a major ☐ priority/ a minor ☐ priority for our service.

2.4 Presenting information for patients who are 'experts' is: a major ☐ priority/ a minor ☐ priority for our service.

2.5 Communicating the risks of treatments or procedures is: a major ☐ problem/ a minor ☐ problem.

2.6 Briefing a designer to produce leaflets (for example) is: a major ☐ problem / a minor ☐ problem.

2.7 OTHER: Please give details of any other major problem or priority for your service?

QUESTION 3: Your views on the support and training required for you and your staff.

3.1 Has your service used any of the following guidelines?

DoH toolkit for producing patient information (NHS identity website). ☐

Centre for Health Information Quality ('Hi Quality') website. ☐

King's Fund 'Producing Patient Information'. ☐

Have you used other guidelines? ☐ YES ☐ NO

If YES, please give brief details.

3.2 Do you use 'templates' for producing information for patients and the public? ☐ YES ☐ NO

If YES, who provided the templates?

3.3 Have you sent staff on workshops or other training events? ☐ YES ☐ NO

If YES, who provided the training (up to three main providers only)?

- 1.
- 2.
- 3.

3.4 Staff may need specific one-off support and training in some aspects of producing information, but sometimes ongoing support may be more appropriate. Sometimes both may be necessary. Please indicate your views.

Involving health professionals requires ☐ specific training ☐ ongoing training/support ☐ both.

Involving patients and the public requires ☐ specific training ☐ ongoing training/support ☐ both.

Writing 'readable' text requires ☐ specific training ☐ ongoing training/support ☐ both.

Ordering text and graphics requires ☐ specific training ☐ ongoing training/support ☐ both.

Adopting an appropriate style for the audience requires ☐ specific training ☐ ongoing training/support ☐ both.

Presenting statistics and some of the 'evidence' requires ☐ specific training ☐ ongoing training/support ☐ both.

Making appropriate use of multimedia requires ☐ specific training ☐ ongoing training/support ☐ both.

3.5 Have you any other comments on the support and training required and offered?

QUESTION 4: Quality assurance for producing information for patients and the public.

4.1 Do you use any readability (eg. Flesch?) checks? ☐ YES ☐ NO

4.2 Do you ask a health professional and/or patient panel to check through drafts? ☐ YES ☐ NO

If YES, what are the main things you ask them to do?

4.3 Have you developed a checklist of your own? ☐ YES ☐ NO

4.4 Do you ask consultants to review your leaflets? ☐ Yes always
☐ Yes sometimes ☐ Rarely or never.

Have you any other comments on the quality assurance process, and how you check you are complying with your own inhouse (or external) guidelines?

Thank you for your valuable time. All the information you supply will be kept confidential and all data non-attributable.

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Appendix 3 Literature overview

The literature review was brief, and provided an overview of the following questions:

- Are resources to support the production of information for patients and the public necessary?
- What are the main problems?
- What are the possible solutions?

Emphasis was placed on locating surveys of practice, evaluation studies and good quality reviews. The time period for the review was 1995 onwards, and the resources included NeLH resources, MEDLINE and personal collections.

<i>Statement/question</i>	<i>Supporting evidence</i>
Patient information leaflets – are they to inform or empower?	Analysis of publications distinguishes two discourses: passive patients to be informed (mechanistic) and patient empowerment (democratisation) ⁵ Information for patients not a given ‘truth’ ⁶
Central guidance/support is necessary for health professionals	and for Royal College of Anaesthetists’ lead in producing patient information ⁷ Informing, communicating and sharing decisions with people who have cancer – requires training and support for health professionals ⁸
Patient information leaflets are often ‘unreadable’	Examples from a large literature include: Nurses often produce leaflets of low readability ⁹ Informed consent form ‘advice’ falls short of readability standards ¹⁰ Australian rheumatologists produced leaflets difficult to read – and important information may be omitted ¹¹ A more readable version of a leaflet preferred by patients ¹²

⁵ Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Soc Sci Med* 2001; 52(9): 1417-1432.

⁶ Payne SA. Balancing information needs: dilemmas in producing patient information leaflets. *Health Informatics J* 2002; 8(4): 174-179.

⁷ Thoms GM, McHugh GA, Lack JA. What information do anaesthetists provide for patients? *Br J Anaesth* 2002; 89(6): 917-919.

⁸ Informing, communicating and sharing decisions with people who have cancer. *Effective Health Care* 2000; 6(6).

⁹ Mumford ME. A descriptive study of the readability of patient information leaflets designed by nurses. *J Adv Nurs* 1997; 26(5): 985-991.

¹⁰ Paasche-Orlow MK, Taylor HA, Brancati FL. Readability standards for informed-consent forms as opposed to actual readability. *N Engl J Med* 2003; 348(8): 721-726.

¹¹ Buchbinder R et al. Readability and content of supplementary written drug information for patients used by Australian rheumatologists. *Med J Aust* 2001; 174(11) 575-578.

Evidence-based leaflets -promote informed choice, if the leaflets complement existing practices?	<p>Evidence based leaflets did NOT promote informed choice among women using maternity services¹³, but there were problems with the intervention which promoted ‘informed compliance’ rather than informed choice¹⁴</p> <p>An RCT of a novel educational booklet for patients with back pain was effective¹⁵</p> <p>RCT of easy to read informed consent statement for clinical trial participation resulted in lower anxiety and more satisfaction¹⁶</p> <p>Patient choice modules proposed for summaries of clinical effectiveness¹⁷</p>
Information about risk is not conveyed well, leaflets may not contain sufficient information	<p>Risk of breast cancer (given normal and abnormal test results) not included in screening literature¹⁸</p> <p>Women in early pregnancy shocked about presentation of evidence on effectiveness of routine ultrasonography, but thought it appropriate to include both advantages and disadvantages (ultrasonographers thought women would become anxious)¹⁹</p> <p>Information on abortion –leaflets (on average) provided only half the possible information²⁰</p> <p>Leaflets on hypertension of variable quality²¹ (assessed using rating scale)</p> <p>Patients not fully aware of the implications of the metered-dose inhaler CFC phaseout²²</p> <p>Consideration of ‘framing’ and visual aids for explaining risk^{23 24}</p>

¹² Butow P et al. *Patient Educ Couns* 1998; 33(2): 129-141.

¹³ O’Cathain A et al. Use of evidence based leaflets to promoted informed choice in maternity care: randomised controlled trial in everyday practice. *BMJ* 2002; 324(7338): 643

¹⁴ Stapleton H, Kirkham M, Thomas G. Qualitative study of evidence based leaflets in maternity care. *BMJ* 2002 324(7338): 639.

¹⁵ Burton AK et al. Information and advice to patients with back pain can have a positive effect. A randomized controlled trial of a novel educational booklet in primary care. *Spine* 1999; 24(23): 2484-2491.

¹⁶ Coyne E et al. Randomized controlled trial of an easy-to-read informed consent statement for clinical trial participation: a study of the Eastern Co-operative Oncology Group. *J Clin Oncol* 2003; 21(5): 836-842.

¹⁷ Holmes-Rovner M et al. Patient choice modules for summaries of clinical effectiveness: a proposal. *BMJ* 2001; 322: 664-667

¹⁸ Croft E, Barratt A, Butwo P. Information about tests for breast cancer: what are we telling people? *J Fam Pract* 2002; 51(10): 858-860.

¹⁹ Oliver s et al. Informed choice for users of health services: views on ultrasonography leaflets of women in early pregnancy, midwives and ultrasonographers. *BMJ* 1996; 313(7067): 1251-1253.

²⁰ Wong SS. Reports from the Faculty of Family Planning and Reproductive Health Care AGM, May 2002. Assessing the quality of information leaflets about abortion methods in England and Wales. *J Fam PlannReprod Health Care* 2002; 28(4): 214-215.

²¹ Fitzmaurice DA, Adams JL. A systematic review of patient information leaflets for hypertension. *J Hum Hypertens* 2000; 14(4): 259-262.

²² Assessment of the readability and comprehensibiliyt of a CFC-transition brochure. *Ann Allergy Asthma Immunol* 2000; 84(2): 211-214.

²³ Edwards A, Elwyn G, Mulley A, Explaining risks: turning numerical data into meaningful pictures. *BMJ* 2002; 324: 827-830.

²⁴ Edwards AGK et al. The effectiveness of one-to-one risk communication interventions in health care: a systematic review. *Med Decis Making* 2000; 20: 290-297.

User involvement in necessary	ad and neck cancer patients ²⁵ Validated booklet preferred by clinicians and patients ²⁶
Tools for assessing the quality of written information are effective, guidelines can work	DISCERN ²⁷ Readability and Processability Form (for informed consent documents) ²⁸ Linguistic analysis ²⁹ Use of questionnaires and focus groups ³⁰ Revision of PILs produced more understandable PILs ³¹
Typeface and colour – some clear preferences only?	Survey of patient package leaflets ³²
Patients tend not to retain information even with leaflets?	Large amount of literature on the problems of ‘informed consent’ – but search premise may sometimes be unrealistic, research design may be questionable Review of obtaining informed consent from older adults ³³ Review of the usefulness of patient information leaflets ³⁴

²⁵ Semple CJ, McGowan B. Need for appropriate written information for patients, with particular reference to head and neck cancer. *J Clin Nurs* 2002; 11(5) 585-593.

²⁶ Joshi HB et al. The development and validation of a patient-information booklet on ureteric stents. *BJU* 2001; 88(4): 329-334.

²⁷ Rees CF, Ford JE, Sheard CE. Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. *Patient Educ Couns* 2002; 47(3): 273-275.

²⁸ Philipson SJ et al. *J Invest Med* 1999; 47(9): 468-476.

²⁹ Bjorn E, Rossel P, Holm S. Can the written information to research subjects be improved? – an empirical study. *J Med Ethics* 1999; 25(3): 263-267.

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